

For Health of The Nation, Unite Online: Medical controversies, civil disobedience and the future of democracy in the light of expert authority crisis

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Proceedings of the Weizenbaum Conference 2021

Democracy in Flux

Order, Dynamics and Voices in Digital Public Spheres

For Health of The Nation, Unite Online

Medical controversies, civil disobedience and the future of democracy in
the light of expert authority crisis

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Digitalization of knowledge means that Kazimierz can open a browser, than a search engine, type in “rush on an forearm”, go to Google Pictures and look for similarities with what his grandson developed overnight. Moreover, it means that his wife, Beata, who is equally skeptical of the public healthcare system, can pick up her smartphone, go to Facebook, and ask one of the many health advice groups, what might have caused the rash, posting pictures and detailed descriptions. “Doctors don’t have time for patients, they just cure effects, not the cause”, she says, “I want the whole truth, I want the facts”. Across the Polish-speaking Facebook, complementing the already popular health-related portals, blogs, forums, as well as Wikipedia, various self-help groups grow in number and size. Some are in favor of conventional medicine, but many are not, pointing out all those “inconvenient truths” of the “health industry”, once hidden and now finally known to people – thanks to the Internet. They can be as big as having hundred thousand members, or as small to only count couple thousands. Either way, their popularity I have observed over the years, skyrocketed in the pandemic. New groups emerged, old expanded to incorporate a new wave of members, people whose trouble in accessing healthcare, or getting care that satisfies their needs grew exponentially since the late winter of the 2020.

In Poland over the past decade the Internet has become the place to go, when seeking health advice. Like elsewhere across the globe, it has also become a source of information on the malfunctions of both, the healthcare and the pharmaceutical industry. While old media have their gatekeepers and their agendas, the Web, even though being fundamentally in private ownership, creates networked spaces where various Internet users can, in various forms, to various degrees, and on various levels of anonymity, prod-use Internet’s content (Bruns, 2016). It became an open-ended learning place, and a place of encounters, where Beata can meet others, who also seek health advice across not only new medical information outlets or Wikipedia, but also within social networking sites such as Facebook or Instagram, social news aggregators such as Reddit, or group instant messaging apps such as WhatsApp, Telegram or Messenger. This paper builds on a long-term ethnographic fieldwork, that took place in years 2016-2020 across the Polish-speaking Internet-scape, inquiring into networked health activism within Internet’s networked publics, that those social media constitute (boyd, 2011; Papacharissi, 2002). In Poland, they revolve around Facebook, and this platform, was my primary focus of the study. Relationships that take place within those spaces, are what I have come to call the new public care.

The new public care is a concept that captures relations of advice, support, and care, that materialize through affordances, and communication infrastructures, of the social media that mediate the information exchange. It describes both the self-care and community-care of Internet users, as it is usually the self-interests that makes help-seekers become members of such care communities; some of them repay the support received, sharing their knowledge – experiences, or information obtain other way, through online searchers, doctor consultations, friend’s stories. The new public care as a concept has three folds to it.

First, there is the care, the same one that makes up the definition of the modern healthcare system. Those informal health advice groups and networks, whether big or small, provide a safe space to ask questions, seek opinion, reference, solution, providing swift answers from other group members, non-experts, lay public, patients. Bottom-up, grass-root organized, they provide what malfunctions and inefficiencies of the public healthcare system cannot. On the one hand, it’s the quick advice of what to do, where to look further, what to Google. On the other, however, it’s attention, often extensive, emotional support, and a remedy for the feeling of hopelessness, desperation or despair they come to those groups with, after being, for various reasons disappointed or confused by the public or private healthcare, or the biomedicine as such.

Second, those care practices take place in what Zizi Papacharissi have called the public sphere of the Digital Age – on the Internet. Informal health advice networks provide an ad to the national healthcare system, that is used by the majority of the society, as every Polish citizen is eligible. It's primary malfunction are the waiting lines, that in the case of more advanced health problems can make a patient wait for years. While there isn't much difference in the quality of service, private healthcare offers no lines, but at a substantially higher cost. Networked publics across social media are the public sphere where grassroots health advice tries to fill in for the failures of the state.

Third, the new public care that relays on knowledge exchange between individuals, creates a hive mind repository of knowledge that provides information from outside of the biomedical hegemony. Alongside YouTube and various webpages, Facebook plays a crucial role in being the main provider of information on the short-comings of the so-called "health industry", that wouldn't be found in mainstream media, except in a few left-wing or right-wing niche magazines. While experts are (usually) well aware of the "imperfections" in their respective fields, the so-called "lay public" expresses feelings of unease, confusion, uncertainty, fear, and anger across the cyberspace, often turning their interest towards alternative health practices, seeking remedies the biomedicine has so far failed to provide them with.

Beata in her post to a Facebook group that brings together Internet users with various stands on biomedicine, learned that her grandson could have had an allergic reaction to food, clothes, chemicals, animals, plants, but also stress. She received advice on home made cures to take care of the rash, and based on the comments under her post, she decided to convince her daughter to take Jaś to see a allergologist, an expert in allergy detection, privately of course. When she first joined the group she was at first overwhelmed with the stories she read, shared news articles that talk about the dark side of the pharmaceutical industry, medical mistakes, corruption in healthcare, and that the scientific process of knowledge-making is a work-in-progress, with many more unknowns than "facts. While the ethnographic methods strength lays in choosing quality over quantity, a scale and sheer number of various grass-root health advice places across the Web seem to suggest a growing need for a reform that would change medical practices more radically than just fixing waiting lines. The democratization of the access to information that the digital age supposedly brought, allowing Beata and others to seek information on their own, having only their habitus, cultural and social capital as points of reference on where to go, made the expert authority crisis of the era of reflexive modernization more visible (Beck i in., 1994). The Web is collectively produced, hence, to that seemingly infinite repository of information anyone can contribute. The Internet is full of various forms and kids of knowledge, some of which are not in line with academic sciences, being not evidence-based.

Annemarie Mol in her concept of body multiple, points to complexity of bodily experiences of sickness that make diagnosis and treatment difficult (Mol, 2002). Many of my interviewees talk about their reasons for seeking advice in health advice groups as being more trusting of experiences of others, even if they recommend cures that are not approved by the hegemonious biomedicine. As they felt unheard and misunderstood by medical doctors, they decided to take matter of their health in their own hands, with Internet repositories helping them to perform their agency. In modern democracies experts are those who inform public policies – experts understood as professionals, individuals who either through their experience or academic education gained extensive knowledge of a given topic (Collins & Evans, 2008). With power relations around knowledge categories changing, how should the democratic state address that the demos is multiple when it comes to their healthcare choices? Bringing in examples that include the controversial anti-vaccination movement, but also the Lyme disease, gluten intolerance, and Hashimoto disease, I argue that the future of healthcare in a democratic society must address the ambiguity of expertise.

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